


# Social barriers influence inflammatory bowel disease (IBD) outcomes and disproportionately affect Hispanics and non-Hispanic Blacks with IBD

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## Abstract

**Background:** The impact of social determinants of health in inflammatory bowel disease (IBD) remains understudied. We evaluated the impact of social barriers on IBD outcomes within a diverse cohort of patients.

**Methods:** We performed a cross-sectional study on adult IBD patients and assessed known social determinants of health. We calculated the total prevalence of these barriers in the sample as a whole and within each ethnic group. We summed the number of barriers present for each individual to create a cumulative social barrier score (SBS), and we evaluated the relationship of each barrier and of the cumulative SBS with IBD outcomes, including disease activity and depressive symptoms.

**Results:** A total of 316 patients were included in the study. Disparities in the prevalence of social barriers emerged by ethnicity: non-Hispanic Blacks reported the greatest number of social barriers, followed by Hispanic patients. Prevalent social barriers included financial strains (38.4%), such as food insecurity, medical care delays (~30%), and low educational attainment (26.8%). Social barriers associated with poor IBD outcomes included low educational attainment, poor health literacy, and financial insecurity. High SBS was associated with greater depressive symptoms [odds ratio (OR) 1.94, 95% confidence interval (CI) 1.21–2.9,  $p = 0.001$ ] and lower reported use of medications. Greater ulcerative colitis (UC) disease activity was observed in patients with greater SBS. No associations were identified between SBS and IBD surgeries, hospitalizations, or disease location.

**Conclusion:** Our study identifies social barriers that may impact IBD care and are disproportionately higher in non-Hispanic Blacks and Hispanics in the United States. Future studies should focus on implementing interventions to reduce these barriers and improve delivery of care.

**Keywords:** depressive symptoms, financial insecurity, inflammatory bowel disease, minorities, social determinants of health

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## Introduction

Inflammatory bowel diseases (IBD) are chronic, immune-mediated diseases associated with high morbidity.<sup>1</sup> In the last decade, research has focused on deciphering the complexities of polygenic risks,

the interplay of genes with the environment, and the downstream effects of these exposures on the intestinal microbiome. Although clinical trials are able to identify effective therapies, high costs often hinder patients' ability to access them.<sup>2</sup> Therefore,

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it is critical to understand social determinants impacting IBD patient care to develop strategies to reduce these observed disparities. Studies examining social determinants of health (SDoH) across a variety of chronic diseases suggest that SDoH play important roles vis-à-vis outcomes.<sup>3,4</sup> This pattern is perhaps most notable in the cardiovascular literature, in which one recent study found that a higher cumulative burden of social barriers was associated with increased readmission rates for patients with congestive heart failure.<sup>5</sup>

Thus far, only a handful of IBD studies have examined the prevalence of SDoH and its influence on disease complications. A Canadian study<sup>6</sup> found that lower socioeconomic status resulted in increased rates of outpatient physician visits, hospitalizations, narcotic use, and use of psychotropic medications among 9298 Manitoba residents with IBD. Similarly, a study examining data from the 2015 National Health Interview Survey<sup>7</sup> found that 12% of US IBD patients reported both food insecurity and lack of social support. Results from these studies underscore the importance of examining SDoH among IBD patients and, particularly, how social barriers may lead to detrimental outcomes such as depression, hospitalizations, surgeries, and flares in this patient population. These studies, however, are limited by use of national claims data and may also underrepresent minorities, who historically have lower rates of response to census and national surveys.<sup>8</sup>

In our study, we performed a comprehensive evaluation of established SDoH including education level, health literacy, financial and food insecurity, and nativity (US/foreign-born status) in a South Florida population of IBD patients. We sampled from an ethnically diverse clinic cohort of patients and examined social barriers by ethnicity and race. We then calculated a total social barriers score (SBS) by summing the presence of total social barriers as previously described<sup>9</sup> and examined the impact of cumulative barriers on outcomes including depressive symptoms, perceived health status, IBD-related complications (surgeries, hospitalizations), and disease activity.

## Methods

### *Study design and setting*

We performed a cross-sectional study of adult patients with an established diagnosis of IBD

[ulcerative colitis (UC) or Crohn's disease (CD)] seen at one of the three gastroenterology clinics between 1 April 2019 and 1 March 2021. These clinic sites included a tertiary referral center, a private gastroenterology (GI) community practice, and a safety-net county hospital-affiliated GI clinic. After providing informed consent, patients completed an IBD intake form capturing their IBD history, including past surgeries, hospitalizations, history of medications used, and detailed demographic information including highest educational degree obtained, insurance status, marital status, smoking history, ethnicity (self-identified), and years lived in the United States. Patients were also asked to complete an SDoH survey as detailed below. Paper surveys were completed by participants at the time of clinic or infusion appointments and were administered by a bilingual research coordinator who was available for assistance with survey completion, if needed. Patients were recruited consecutively in clinic if they agreed to complete the survey. We collected Census-based block-level information to obtain the median household income using each patient's zip code. Providers recorded information including IBD phenotype, disease severity, history of IBD-related complications, and validated disease activity indices. Using this information, we calculated the Harvey-Bradshaw Index (HBI) score for CD, as well as the simple clinical colitis activity index (SCCAI) score for UC.

### *Ethical considerations*

All participants were adults and were asked to provide informed consent. Ethical approval for our study was obtained from our local institutional review board (IRB): IRB study ID 20081100, amendment approved 1/25/2021. All patient data were deidentified in our database.

### *SDoH survey*

We created a survey (Appendix 1) using an adapted set of SDoH measures proposed by the National Academy of Medicine *Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records*.<sup>10</sup> Specific SDoH assessed included the education level, financial strain or hardship paying for basics such as food and medications, food insecurity, social isolation, overall health literacy, access to health care, and housing security (whether or not participants had housing at present or were worried

about losing their home in the future).<sup>11</sup> Social isolation was measured using several questions, including attendance at social gatherings, meetings/social events, and frequency of weekly interactions with family and friends (by phone or in person). Social isolation is considered a social barrier, with prior studies demonstrating the negative effects of isolation on various health outcomes. In addition, questions were added to address specific social factors particular to our large immigrant Hispanic population, such as whether or not respondents were born in the United States and, if not, number of years lived in the United States. We excluded questions, such as domestic violence, that would necessitate an immediate health system reaction. After the first 100 patients, we shortened the original survey to facilitate completion. We retained questions that differed across ethnicity or that were important to consider in terms of their relationship to IBD outcomes. In the process, we kept the question asking whether participants lived alone, but we removed questions on number of people living in the home and on number of rooms in the home.

### *SDoH*

To evaluate the negative impact of cumulative social barriers on IBD outcomes, we created a social barriers score (SBS). We dichotomized the answers to each question in the survey to create final SBS as shown in Table 1. For each social determinant, we assigned 1 point if the negative social barrier was present and 0 otherwise (for question response groupings, see Table 1). We then calculated the sum of all social barriers to create a cumulative SBS. Scores ranged from a minimum of 0 to a maximum of 10 points, with higher scores representing an increased number of social barriers. We calculated total SBS based on previous literature indicating that the cumulative burden of social barriers had greater impact on cardiovascular outcomes than did each barrier individually.<sup>9</sup> Patients missing data on any of these variables were excluded from the analyses. We then examined the cumulative SBS as a continuous variable to correlate with baseline characteristics and with each IBD outcome. Tertiles for the SBS score were also calculated and correlated with outcomes.

### *Outcome measures*

We examined the relationship between cumulative SBS and several IBD-related outcomes. These

outcomes included disease activity at time of the questionnaire (using HBI for CD and SSCAI for UC), lifetime history of IBD-related hospitalizations, IBD-related surgeries, steroid use, narcotic use, symptoms of depression, stress, and overall perceived health status. To gauge symptoms of depression, we used the PHQ-2, an abbreviated version of the patient health questionnaire (PHQ-9) specifically querying whether, in the last 2 weeks, they (1) had little interest or pleasure in doing things and (2) were feeling down, depressed, or hopeless.<sup>12</sup> Participants could answer ‘not at all’, ‘several days’, ‘more than half the days’, and ‘nearly every day’. For the purposes of our analysis, we dichotomized depressive symptoms responses as 1 if participants provided any response other than ‘not at all’ and 0 if they answered ‘not at all’.

*Statistical analysis.* The reporting of this observational study conforms to the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) statement for cross-sectional studies<sup>13</sup> (Suppl Fig 1). Descriptive variables were analyzed by ethnicity and race using chi-square, or student’s *t* test or analysis of variance (ANOVA), for categorical and continuous variables, respectively. Fisher’s exact test was used to compare proportions in cases where expected cell counts were less than 5. Binary and multinomial regression analyses were performed to measure associations of demographic variables (e.g. race, ethnicity, income, nativity, location of clinic) and individual SDoH indicators with total SBS. Logistic and ordinal regression analyses were performed for categorical/binary and ordinal dependent outcome variables, respectively. General linear models were performed to ascertain the association of total SBS with continuous dependent variables, including disease activity indices (HBI and SSCAI). We incorporated significant demographic correlates from our univariate models into our multivariable regression analyses. A value of  $p < 0.05$  was used to denote statistical significance. Statistical analyses were performed using SAS. Institute Inc. 2014.<sup>14</sup>

## **Results**

### *Baseline characteristics*

A total of 316 patients completed the SDoH survey. More women completed the survey than men (56.3% *versus* 43.7%). Most of the surveyed

**Table 1.** Social determinants of health (SDoH) domains used to create a composite social barrier score (SBS).

Domain	Reference answer	Presence of SDoH risk
Nativity	Born in the United States	Foreign born
Education level	Some college or more	High school or less
Housing	Has a home	Has no home or is at risk of losing home
Confident filling forms	Quite and extremely comfortable	Not at all, little, or somewhat
Financial strain	Not hard paying for basics	Somewhat and very hard
Talk on the phone with relatives or friends	Once or more a week	Less than once a week
Get together	Once or more a week	Less than once a week
Attend church	4 or more times a year	Less than 4 times a year
Attend meetings	4 or more times a year	Less than 4 times/year
Delaying medical care in the past 12 months	No	Yes

patients identified as White (89.22%), and 42.39% identified as Hispanic. Table 2 provides detailed demographic information, and we identify disparities in income and educational attainment by race and ethnicity. The mean age of our cohort was 42.89 years (SD 15.2), and the mean age at the time of IBD diagnosis was 30.21 years (SD 14.63). Approximately 55.95% of patients had CD, and 34.83% had active disease defined by clinical symptoms using the SSCAI for UC or HBI for CD at time of survey.

#### *Prevalence of social barriers in our IBD cohorts*

The prevalence of all SDoH domains in the cohort is shown in Figure 1. Participants reported a mean of 3.25 social barriers (SD 1.72). When stratified by ethnicity, non-Hispanic Blacks had the greatest mean total burden of 4.50 (SD 1.72), followed by Hispanics [mean 3.87 (SD 1.88)], and non-Hispanic Whites [mean 2.66 (SD 1.45)],  $p < 0.0001$  (see Figure 2). For patients born outside the United States, duration in the United States reduced the burden of social barriers such that for every year in the United States, the total cumulative burden of social barriers (SBS) decreased by 0.0168 [ $F(1,257) = 10.92$ ,  $p = 0.0011$ ]. Furthermore, when we stratified the sample by SBS tertiles, Hispanics were more likely to be grouped into the highest tertile of SBS

compared with non-Hispanic Whites (OR 2.67, 95% CI 1.38–5.17,  $p = 0.0036$ ), over and above the contributions of income and clinic location.

We found that greater than one-third of patients experienced financial strain, and such strain was observed among greater proportions of Hispanics (56.25%) and non-Hispanic Black (40.0%) patients compared with non-Hispanic Whites (24.85%). A total of 18.2% reported concern regarding ability to pay for food, and 11.6% had run out of food at least once within the year before assessment. Disparities in prevalence of food insecurity were also observed across ethnicity, with non-Hispanic Blacks and Hispanics reporting significantly higher prevalence of food insecurity compared with non-Hispanic Whites [15.2%, 9.1%, and 6.9%, respectively,  $\chi^2(2) = 9.95$ ,  $p = 0.04$ ]. In addition, lack of attendance at social gatherings, religious services, or large social gatherings (meetings/conferences/parties) was common in our cohort of IBD patients (both before and during the COVID-19 pandemic).

We also found that 29.07% of patients reported delaying medical care in the last 12 months, and no differences emerged in prevalence of medical care delay by ethnicity. The most common cause of medical care delay was waiting long hours to see the doctor (15.9%), and only five participants

**Table 2.** Demographic characteristics of our cohort, stratified by ethnicity.

	Total (n = 316)	Hispanic (n = 131)	Non-Hispanic Black (n = 10)	Non-Hispanic White (n = 168)
Female, n (%)	178 (56.3%)	73 (55.7%)	5 (50.0%)	97 (57.7%)
Education <sup>a</sup> , n (%)				
High school or less	78 (24.7%)	46 (35.1%)	6 (60.0%)	26 (15.5%)
College	193 (61.1%)	71 (54.2%)	3 (30.0%)	113 (67.3%)
Advanced degree	17 (5.4%)	6 (4.58%)	0 (0%)	11 (6.54%)
Technical school	3 (0.9%)	2 (1.5%)	0 (0%)	1 (0.60%)
Income <sup>a</sup> , median (IQR)	\$69,414.0 (37,414.0)	\$62,402.0 (27,270.0)	\$60,293.0 (19,613.0)	\$79,804 (41,040)
US-born, n (%)	209 (66.1%)	51 (38.9%)	5 (50.0%)	149 (88.7%)
English as a second language	74 (23.41%)	72 (54.96%)	0	2 (1.19%)
Marital status <sup>a</sup> , n (%)				
Married or living together	106 (33.5%)	42 (32.1%)	0 (0%)	66 (39.3%)
Single	77 (24.4%)	31 (23.75)	6 (60.0%)	40 (23.8%)
Divorced or separated	17 (5.1%)	10 (6.9%)	3 (30.0%)	4 (2.03%)
Smoking history, n (%)				
Active smoking	20 (6.4%)	8 (6.1%)	0 (0%)	12 (7.1%)
Ex-smoker	56 (17.8%)	17 (13.0%)	0 (0%)	38 (22.6%)
Never smoker	238 (75.8%)	106 (80.9%)	10 (100%)	116 (69.0%)
Current age <sup>a</sup> , median (IQR)	42.7 (27.2)	38.0 (24.0)	41.72 (20.3)	46.0 (27.2)
Clinic location <sup>a</sup> , n (%)				
Tertiary referral center	273 (86.39%)	99 (75.6%)	4 (40%)	167 (99.4%)
Safety-net clinic	28 (8.86%)	21 (16.0%)	4 (40%)	0 (0%)
Community GI practice	15 (4.75%)	11 (8.4%)	2 (40%)	1 (0.6%)
IBD type				
Crohn's disease	179 (56.6%)	73 (55.7%)	7 (70%)	93 (55.3%)
Ulcerative colitis	131 (41.4%)	54 (41.2%)	3 (30%)	73 (43.4%)
Indeterminate colitis	6 (1.9%)	4 (3.05%)		2 (1.2%)

ANOVA, analysis of variance; GI, gastroenterology; IBD, inflammatory bowel disease; IQR, interquartile range.  
<sup>a</sup>There are significant differences ( $p < 0.01$ ) on ANOVA comparing variables by ethnic group.

reported 'no access to transportation' as a barrier to receiving medical care. In addition, 22.22% of patients did not feel comfortable completing medical forms. This was particularly true for

Hispanics and non-Hispanic Blacks (27.48% of Hispanics, 50% of non-Hispanic Blacks, and 15.57% of non-Hispanic Whites,  $p = 0.0042$ ). Housing concerns were less common in the



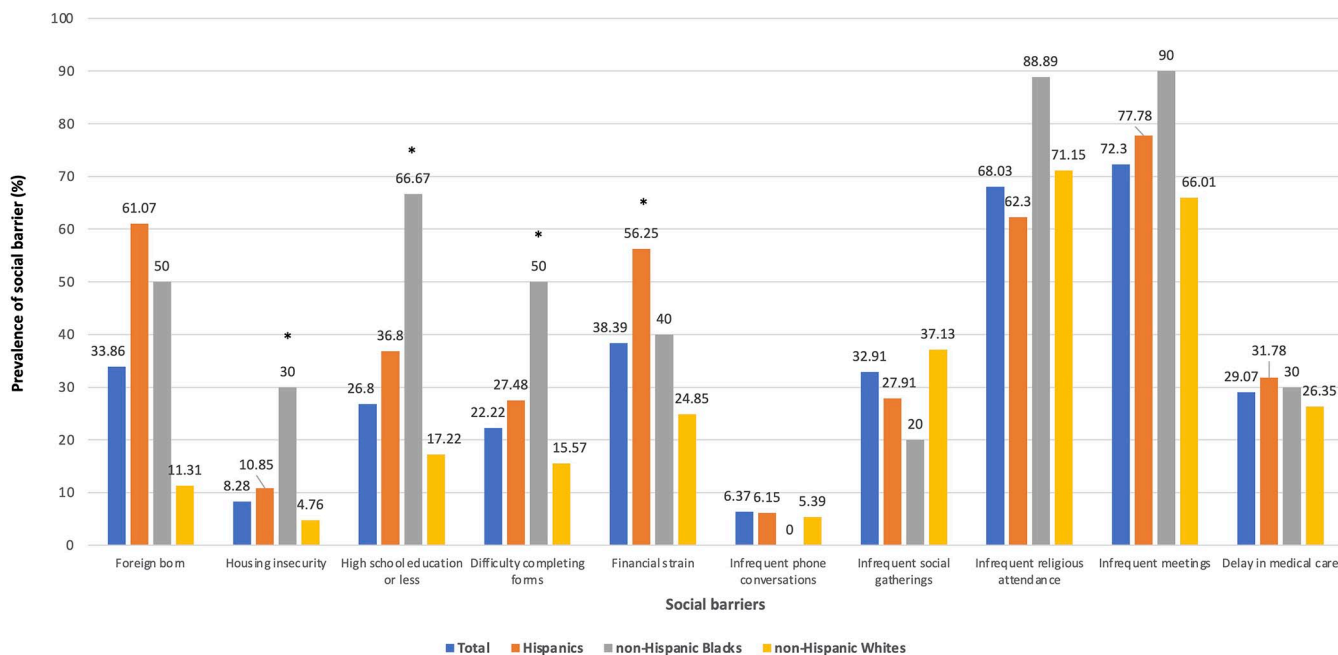


Figure 1. Prevalence of social determinants of health in our IBD cohort.

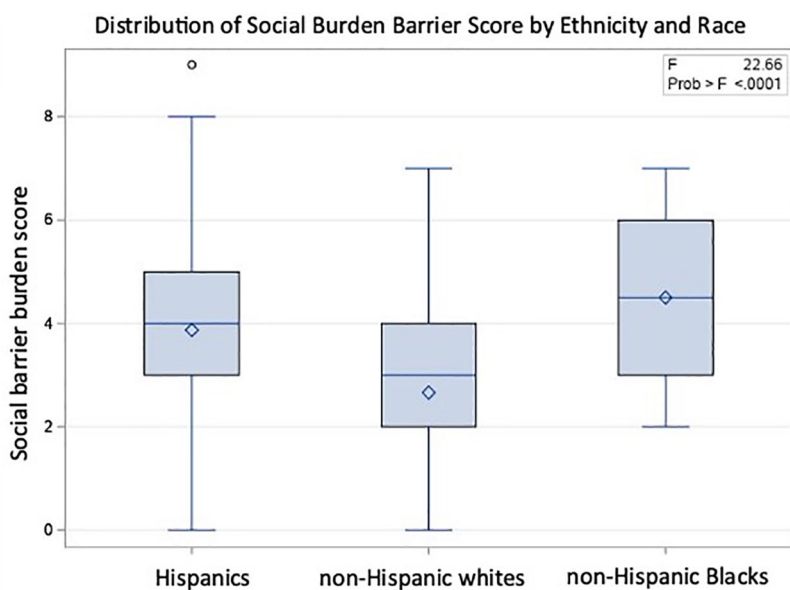


Figure 2. Total social determinants of health stratified by ethnicity.

cohort (8.28%), although disparities in housing insecurity were seen by ethnicity. Housing insecurity was most prevalent in non-Hispanic Blacks

(30%), followed by Hispanics (10.85%) and non-Hispanic Whites (4.76%) (Figure 1).

*Relationship of social barrier score (SBS) with IBD outcomes*

We examined the relationship between cumulative SBS and several IBD-related outcomes, including disease activity at time of the questionnaire (using the HBI for CD and SSCAI for UC), lifetime history of hospitalizations, IBD-related surgeries, steroid use, narcotic use, symptoms of depression, overall perceived health status, and days not felt well in the last 30 days. Higher SBS scores emerged in patients with more active disease in UC, but not in CD. The mean SBS for those with active UC disease was 3.14 (SD 1.80) compared with 2.7 (SD 1.71) in those with inactive disease. There were no associations between UC disease activity and demographic characteristics including ethnicity, clinic location, income, and marital status. Individual barriers independently associated with disease activity were low educational attainment, discomfort completing forms, and lack of socialization with family and friends (Table 3). No significant association emerged between disease activity in CD (as measured by the HBI) and SBS [ $F(1) = 1.69$ ,

**Table 3.** Demographic and IBD-related characteristics stratified by presence of social barriers.

<b>SDoH (columns)</b>	<b>Low educational attainment</b>	<b>Uncomfortable completing forms</b>	<b>Financial insecurity</b>	<b>Delay in medical care by 12 months</b>
Number of social barriers, mean (SD)	4.46 (1.71)*	4.84 (1.75)*	4.36 (1.61)*	4.39 (1.85)*
Divorced or separated, %	46.67	41.12	56.26*	40.0
Safety-net GI clinic, %	53.57	64.39*	71.43*	40.74
Median income (IQR)	61,833* [32,412]	63,653* [34,093]	58,958* [25038]	69,823 [32,777]
UC disease activity via SCCAI, median (IQR)	3.0 (7)*	4.0 (5)*	2.0 (5)	1.0 (3)
Crohn's disease activity via HBI, median (IQR)	3.0 (6)	3.0 (5)	3.0 (6)	4.0 (5)
Depression symptoms, %	41.11*	25.0	57.89*	45.0*
Lifetime IBD hospitalization, %	30.11	24.50	39.90	31.0
Steroids ever, %	23.65	22.73	35.78	28.64
Lifetime IBD-related surgeries, %	33.33	20.21	34.78	28.42
No 5-ASA use, %	41.77*	28.05	64.10*	29.63
No immunomodulator use, %	30.37	27.97	50.35	28.17
No biologic use, %	24.0	31.43	39.42	26.67

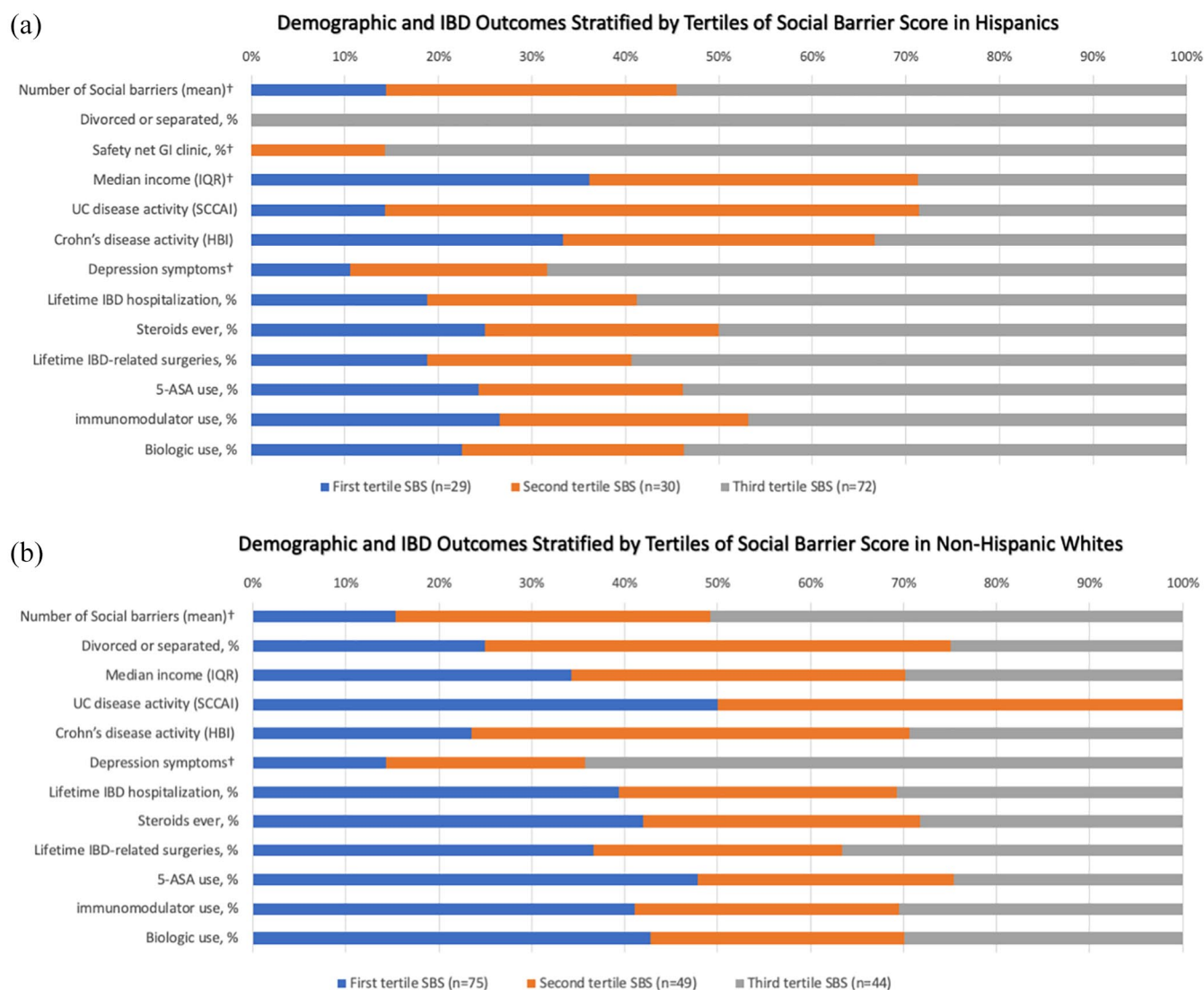
5-ASA, 5-aminosalicylates; GI, gastroenterology; HBI, Harvey-Bradshaw Index; IBD, inflammatory bowel disease; IQR, interquartile range; SCCAI, simple clinical colitis activity index; SDoH, social determinants of health; UC, ulcerative colitis.  
Percentages pertain to row percentages. For example, a total of 46.67% of patients divorced or separated had low educational attainment.  
\*Chi-square tests or *t* test values of *p* values <0.05.

$p=0.19$ ] or between CD and individual social barriers.

Patients with higher SBS were more likely to self-report 'poor overall health' (OR 1.45, 95% CI 1.25–1.69,  $p<0.0001$ ) and higher stress levels (OR 1.23, 95% CI 1.04–1.5,  $p=0.01$ ). However, there were no associations between SBS and IBD complications including IBD-related surgeries (OR 1.05, 95% CI 0.87–1.15,  $p=0.93$ ), steroid use (OR 0.10, 95% CI 0.97–1.27,  $p=0.12$ ), or narcotic use (OR 1.03, 95% CI 0.9–1.18,  $p=0.85$ ). No association was identified between SBS and CD behavior (i.e. fistulizing, stenotic CD) (OR 1.08, 95% CI 0.91–1.28,  $p=0.35$ ) or between SBS and presence of perianal CD disease (OR 0.95, 95% CI 0.79–1.14,  $p=0.57$ ). Similarly, no associations were found between SBS and UC and CD disease location (data not shown).

Patients with higher total SBS were 1.5 times more likely to have depressive symptoms than

those with lower SBS, even after adjusting for foreign born status, marital status, ethnicity, clinic location, and income (OR<sub>adjusted</sub> = 1.94, 95% CI 1.24–2.9,  $p=0.001$ ). The mean total SBS was 4.47 (SD 1.93) among those with depressive symptoms and 3.07 (SD 1.69) among those without depressive symptoms [ $t(314) = 4.78$ ,  $p<0.0001$ ]. Furthermore, we found that Hispanic and non-Hispanic Whites classified into the highest SBS tertile reported the greatest prevalence of depressive symptoms compared with those in the lower and middle tertiles (Figure 3(a) and (b)). Finally, we examined the relationship between SBS and reported IBD medication use. We found that patients with higher SBS reported lower use of 5-aminosalicylates (ASA) (OR 0.82, 95% CI 0.71–0.94,  $p=0.006$ ) and lower immunomodulator use (OR 0.86, 95% CI 0.76–0.98,  $p=0.02$ ). Low educational attainment, difficulty filling out forms, and financial insecurity appeared to be responsible for this association (Table 3). However, no significant association emerged



**Figure 3.** Demographic and IBD outcomes stratified by tertiles of social determinants of health by ethnicity. Demographic and IBD outcomes stratified by tertiles of social barrier score in (a) Hispanics and (b) non-Hispanic Whites.

between biologic use and SBS (OR 0.92, 95% CI 0.81–1.05,  $p = 0.24$ ) or between number of biologics in past and SBS [ $F(1) = 1.15$ ,  $p = 0.28$ ].

### Discussion

This study is the first to examine the presence of SDoH in a comprehensive manner in a diverse cohort of IBD patients, and to determine the cumulative impact of these social barriers on IBD outcomes. We found a high prevalence of social barriers impacting clinical disease activity, overall perceived health status, medication use, and mental health. In addition, our study reports that the most prevalent

social barriers disproportionately affected non-Hispanic Blacks and Hispanics. Common barriers included food insecurity, financial constraints, concerns over ability to afford medical care, and even social isolation. These findings underscore the importance of recognizing social barriers among IBD patients and the need to study and implement care strategies that address these disparities.

Our study found a high prevalence of food insecurity, particularly among non-Hispanic Blacks and Hispanics. Food insecurity is particularly relevant in IBD, given the mounting evidence on the role of diet in inflammation.<sup>15–17</sup> Because food



insecurity is common among IBD patients, future diet recommendations and research should focus on diets that are healthy and affordable. We also found a slightly greater percentage of food insecurity in our cohort (18%) compared with 12% from the 2015 National Health Inpatient Survey (NHIS) data, which could be due to our diverse cohort of patients, who were sampled from community and many of whom are immigrants attending safety-net clinics.<sup>7</sup>

Our study is particularly relevant, given the increasingly ethnically diverse population of IBD patients in the United States. In fact, we find that social barriers disproportionately affect non-Hispanic Blacks and Hispanics with IBD. Our cohort of non-Hispanic Black patients reported proportionally higher prevalence of low educational attainment, lower income wages, and had the highest proportion of patients with housing insecurity, difficulty completing forms, and lack of attendance at large events or religious gatherings. However, we should interpret these results with caution because our sample size of non-Hispanic Blacks was extremely small. Hispanics had the highest prevalence of financial insecurity, perhaps explained by the fact that a large proportion of Hispanics were seen at the safety-net clinic. Although greater duration of time in the United States decreased the number of social barriers, this decrease was very small, and although it was statistically significant, it may not have meaningful socioeconomic implications. We also observed that, compared with non-Hispanic Whites, a greater percentage of Hispanics reported lower educational attainment and greater housing insecurity, difficulty completing forms, and financial insecurity. Therefore, our study provides greater social context of the barriers that our diverse IBD patients encounter.

Despite clear disparities in the prevalence of social barriers, there were also several social barriers with a similar impact across our diverse cohort. We found that a large proportion of patients did not attend large social gatherings, and if their disease was active, patients would socialize with friends and family even less; this observation was true at any time period our questionnaire was filled. Perhaps most importantly, we found that approximately 30% of patients reported delaying medical care by 12 months. Interestingly, we found no differences with respect to delay of care before *versus* during the COVID-19 pandemic,

and it is possible that telemedicine may have minimized delay in medical care during this time.<sup>18</sup> Nevertheless, this broad medical delay should prompt future studies to investigate possible reasons for lack of health care access and for delay of health care beyond financial insecurity.

In this study, we found associations between increased disease activity in UC, depressive symptoms, poor perceived health, increased stress, and higher social barrier burden scores. We also found that patients with a greater cumulative sum of social barriers were less likely to report use of certain IBD medications, in particular 5-ASAs and immunomodulators. When examining social barriers associated with these outcomes, we found that common barriers related to various IBD outcomes were low educational attainment, discomfort completing forms, and financial insecurity. We also found that severe CD behavior, such as perianal disease, was not more common in patients with more social barriers. This finding suggests that severe disease phenotypes observed in specific ethnic or racial groups, such as the higher rates of perianal CD observed in African Americans, may not necessarily result from barriers to care, or delay in care.<sup>19</sup>

Our study is characterized by several limitations that should be considered when interpreting our findings. First, our study was a cross-sectional analysis, so we cannot determine whether an exposure (an SDoH) causes an outcome (such as depressive symptoms). Because we assessed prior disease phenotype and history retrospectively, we are also limited in our ability to evaluate temporal associations between duration of social barriers and presence of IBD-related complications or development of mental health issues. Although we cannot assume directionality or causality, our study nonetheless moves the field forward by identifying disparities and barriers to care that need to be investigated further and acted upon. Second, our total sample size for non-Hispanic Black patients was small. However, even in this small sample, we were able to identify a significant number of social barriers affecting our non-Hispanic Black IBD community that mirror the results of various public health studies.<sup>20–22</sup> Our cohort of participants is also largely representative of patients attending a tertiary referral center (encompassing 86% of our cohort), which can limit generalizability to other clinic cohorts. Nevertheless,

even in an insured population, we identified several negative SDoH, as well as ethnic disparities in these social barriers. Furthermore, because we collected data using a survey and patients' self-reported outcomes, our study is subject to recall bias including number of hospitalizations, surgeries, and patient-reported clinical disease activity. In addition, clinical disease activity measures may not provide the most accurate reflection of inflammation, especially in CD, and may explain why we did not identify associations between SBS and disease activity in CD.

Finally, our data were collated primarily during the COVID-19 pandemic, which may represent a limitation as patients' day-to-day practices may have changed during this time. However, this research highlights an unexpected benefit of analyzing trends in this time, as it is likely that the post-COVID-19 pandemic period represents a 'new normal' for our patients. In this unprecedented new reality, it becomes even more imperative that patient behaviors and SDoH are highlighted to ensure that effective and innovative solutions are implemented to improve healthcare delivery.

In conclusion, our study was among the first to capture the prevalence of relevant social barriers to the delivery of IBD care in an ethnically diverse IBD community and identifies actionable barriers to target that could improve IBD outcomes, including clinical disease activity and mental health. Future studies should focus on implementing interventions focusing on minimizing social barriers to improve healthcare delivery.

#### Author contributions

**Oriana M. Damas:** Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.

**Gabriela Kuftinec:** Conceptualization; Data curation; Investigation; Methodology; Supervision; Visualization; Writing – original draft; Writing – review & editing.

**Nidah S. Khakoo:** Investigation; Methodology; Project administration; Resources; Visualization; Writing – original draft; Writing – review & editing.

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**James Levitt:** Data curation; Investigation; Methodology; Resources; Validation; Writing – review & editing.

**Joanna Lopez:** Data curation; Formal analysis; Investigation; Writing – review & editing.

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**Amar R. Deshpande:** Conceptualization; Data curation; Methodology; Resources; Supervision; Writing – review & editing.

**Seth J. Schwartz:** Conceptualization; Data curation; Methodology; Supervision; Writing – review & editing.

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## Data request

Data, analytic methods, and study materials can be made available to other researchers on request.

## Guarantor of the article

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## Supplemental material

Supplemental material for this article is available online.

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## Appendix 1

### Social determinants of health

Dear Research Participant,

We appreciate your participation in our Crohn’s and Colitis research studies that are part of the University of Miami Crohn’s and Colitis Center. We are deploying a ‘Social Determinants of Health’ that will take less than 5 min to complete.

This will allow us to understand what important factors are responsible for causing inflammatory bowel disease (Crohn’s or ulcerative colitis) or having a flare. As always, we appreciate your response and contribution to our ongoing mission to improving the lives of patients with Crohn’s and ulcerative colitis.

Sincerely, the Crohn’s and Colitis research team

Thank you!

Today’s date	
1. How hard is it to pay for the basics like food, housing, medical care, and heating?	<ul style="list-style-type: none"> <li>• Very hard</li> <li>• Somewhat hard</li> <li>• Not hard at all</li> </ul>
2. Within the past 12 months, you worried that your food would run out before you got money to buy more?	<ul style="list-style-type: none"> <li>• Often true</li> <li>• Sometimes true</li> <li>• Never true</li> <li>• NA</li> </ul>
3. Within the past 12 months, how often did the food you buy not last and you didn’t have money to get more.	<ul style="list-style-type: none"> <li>• Often true</li> <li>• Sometimes true</li> <li>• Never true</li> <li>• NA</li> </ul>
4. a. Over the last 2 weeks, how often have you been bothered by any of the following problems – little interest or pleasure in doing things?	<ul style="list-style-type: none"> <li>• Not at all</li> <li>• Several days</li> <li>• More than half the days</li> <li>• Nearly every day</li> </ul>
4. b. Over the last 2 weeks, how often have you been bothered by any of the follow problems – feeling down, depressed, or hopeless	<ul style="list-style-type: none"> <li>• Not at all</li> <li>• Several days</li> <li>• More than half the days</li> <li>• Nearly every day</li> </ul>
5. In a typical week, how many times do you talk on the telephone with family, friends on neighbors?	<ul style="list-style-type: none"> <li>• Never/no telephone</li> <li>• Less than 1×/week</li> <li>• Once a week</li> <li>• Twice a week</li> <li>• 3+ times a week</li> </ul>

(Continued)

**Today's date**

- |   |   |
|---|---|
| 6. How often do you get together with friends or relatives?   | <ul style="list-style-type: none"> <li>• Never/no telephone</li> <li>• Less than 1×/week</li> <li>• Once a week</li> <li>• Twice a week</li> <li>• 3+ times a week</li> </ul>   |
| 7. How often do you attend religious services?  | <ul style="list-style-type: none"> <li>• Never/do not belong</li> <li>• Once a year</li> <li>• Twice a year</li> <li>• Three times a year</li> <li>• 4+ times a year</li> <li>• Decline to answer</li> </ul>  |
| 8. How often do you attend meetings of the clubs or organizations you belong to?  | <ul style="list-style-type: none"> <li>• Never/do not belong</li> <li>• Once a year</li> <li>• Twice a year</li> <li>• 3 times a year</li> <li>• 4+ times a year</li> <li>• Decline to answer</li> </ul>  |
| 9. When you go to your doctor's office or to the hospital, are you comfortable filling out medical forms by yourself?   | <ul style="list-style-type: none"> <li>• Not comfortable at all</li> <li>• A little comfortable</li> <li>• Somewhat comfortable</li> <li>• Quite comfortable</li> <li>• Extremely comfortable</li> </ul>  |
| 10. Other than cost, have you delayed getting medical care for one of the following reasons in the past 12 months?  | <ul style="list-style-type: none"> <li>• You couldn't get through on the telephone</li> <li>• You couldn't get an appointment soon enough</li> <li>• Once you got there, you had to wait too long to see the doctor</li> <li>• The clinic or doctors office wasn't open when you could get there</li> <li>• You didn't have transportation</li> <li>• No, I did not delay getting medical care/did not need medical care</li> </ul> |
| 11. Would you say that in general your health is  | <ul style="list-style-type: none"> <li>• Excellent</li> <li>• Good</li> <li>• Very good</li> <li>• Fair</li> <li>• Poor</li> <li>• Don't know/not sure</li> <li>• Decline to answer</li> </ul>  |
| 12. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? | <ul style="list-style-type: none"> <li>• Number of days</li> <li>• None</li> <li>• Don't know/not sure</li> <li>• Decline to answer</li> </ul>  |
| 13. What is your housing situation today?   | <ul style="list-style-type: none"> <li>• I do not have housing (staying with others, in a hotel, in a shelter, outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)</li> <li>• I have housing today, but I am worried about losing housing in the future</li> <li>• I have housing</li> </ul>   |

*(Continued)*



Today's date					
14. Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his or her mind is troubled all the time. Do you feel this kind of stress these days?	<ul style="list-style-type: none"> <li>• Not at all</li> <li>• Somewhat</li> <li>• Very much</li> <li>• A little bit</li> <li>• Quite a bit</li> </ul>				
15. How often do you or your family go out to eat or bring home ready-to-eat foods from ...?					
	<b>Never</b>	<b>&lt;1×/week</b>	<b>1-2×/week</b>	<b>3-4×/week</b>	<b>5+×/week</b>
a. Relatives/Friends homes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Fast food restaurants (including Latin and Chinese food)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Sit down restaurants (with table service)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Buffet restaurants (including Chinese buffet)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Pick up and take home restaurants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Grocery stores (hot or cold ready to eat food)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Cafeterias (school or work)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Vending machines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. On street vendors (including trucks, carts and wagons)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Other (e.g. quick marts, bakeries, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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